

Seeing the Face of the Patient: Considerations in Applying Bioethics Mediation to Non-Competent End-of-Life Decisionmaking

MATTHEW BIERLEIN*

For Theresa Marie Schiavo, good science, good medicine, and the careful application of the law were not enough. Her loving parents begged the world to save the life of their brain-damaged daughter, while her devoted husband sought removal of a feeding tube to fulfill what he believed were his wife's wishes not to be maintained in a diagnosed vegetative state. As the whole world watched, legal and political armamentaria were mightily assembled and deployed.¹

End-of-life ("EOL") decisionmaking confronts families and friends with emotional choices regarding life and death. This decisionmaking process exposes loved ones' most intimate thoughts and feelings. While these feelings are deeply personal, the case of Theresa Schiavo illustrates how the EOL decisionmaking process, at its end, may thrust the intimate details of loved ones' lives into a public setting—transforming an intensely personal experience into a "national nightmare."² In light of the possibility of a

* J.D., The Ohio State University Moritz College of Law, 2006. B.A. in Computer Science, College of Wooster, 2001. The author is an attorney in Columbus, Ohio, and the views expressed herein are solely those of the author and are not intended to reflect the views of his employer or its clients. I would like to thank Amy Cohen for her encouragement in pursuing publication of this article and for her valuable feedback on earlier drafts. I would also like to thank the JDR staff for their hard work in bringing this article to publication.

¹ Jay Wolfson, *Erring on the Side of Theresa Schiavo: Reflections of the Special Guardian ad Litem*, HASTINGS CENTER REPORT, May–June 2005, at 16. Jay Wolfson was Theresa Schiavo's guardian ad litem.

² A LexisNexis search of the New York Times and The Washington Post of the last two years returned nearly one thousand hits for the name "Schiavo." Illustrative of how far the Schiavo case extended into the public and political conscience, Michael Schiavo, Terri's husband, has since started a political action committee, called Terri PAC, for the purpose of supporting or opposing candidates based on where they stood on the Schiavo case. See *Retaliation in Right-to-Die Case*, N.Y. TIMES, Dec. 9, 2005, at A3. Announcing the formation of the PAC, Mr. Schiavo stated, "I have taken my sadness, anger and worry and channeled them into a personal resolution: I will do everything in my power to keep another unsuspecting American family from reliving our private *national nightmare*." *Id.* (emphasis added). See also Terri PAC Home Page, at <http://www.terripac.com/>.

"nightmarish" end, hospitals³ continue to scrutinize and explore the EOL decisionmaking process for opportunities to prevent this result. Bioethics mediation presents such an opportunity.

I. INTRODUCTION

This paper proposes rethinking the ethical principle of autonomy and the theory of mediation to strengthen bioethics mediation and enhance its usefulness for resolving EOL decisionmaking disputes. Several commentators have proposed mediation as an option for resolving EOL care disputes.⁴ However, this paper argues that as currently implemented, the effectiveness of mediation in EOL dispute settings is severely limited by two factors. First, by a dominant conception of autonomy grounded in personal choice and lacking a more robust inter-subjective ethical vision that could meaningfully preserve autonomous decisionmaking even in instances of individual incompetence. Second, by a dominant conception of mediation that aims to help the parties find expansive and creative options to resolving their disputes, and that is therefore inappropriate in the context of the limited choices inherent to an EOL care dispute.

This paper challenges the limitations inherent to these traditional understandings and proposes a more robust conceptualization of bioethics mediation apt for the EOL dispute resolution context. This approach is termed person-centered mediation.⁵ Drawing on Levinas's conception of ethics⁶ and Bush and Folger's conception of transformative mediation,⁷ this paper proposes a mode of mediation that addresses value-laden disputes involving the treatment or care of an individual. Person-centered mediation focuses on bringing the parties to a dispute to a deeper understanding of the

³ For purposes of this paper, "hospital" is used not only as a literal reference, but as a proxy for similarly situated end-of-life caregiving institutions.

⁴ See generally Alisa L. Geller, *In the Aftermath of the Terri Schiavo Case: Resolving End-of-Life Disputes Through Alternative Dispute Resolution*, 6 PEPP. DISP. RESOL. L. J. 63 (2006); Robert Gatter, *Unnecessary Adversaries at the End of Life: Mediating End-of-Life Treatment Disputes to Prevent Erosion of Physician-Patient Relationships*, 79 B.U. L. REV. 1091 (1999); Diane E. Hoffmann, *Mediating Life and Death Decisions*, 36 ARIZ. L. REV. 821 (1994); I. Glenn Cohen, *Negotiating Death: ADR and End of Life Decisionmaking*, 9 HARV. NEGOT. L. REV. 253 (2004); NANCY N. DUBLER & CAROL B. LIEBMAN, *BIOETHICS MEDIATION: A GUIDE TO SHAPING SHARED SOLUTIONS* (2004).

⁵ See *infra* Part III.B.

⁶ See *infra* Part III.A.ii.

⁷ See *infra* Part III.B.i.

CONSIDERATIONS IN APPLYING BIOETHICS MEDIATION

individual about whom the dispute revolves so as to more effectively reach resolution. To that end, this paper sets forth an ethical response to the limits of autonomy that moves beyond choice and toward a deeper understanding of the essence of the person incapable of exercising his or her autonomy. It explores a vision of mediation that emphasizes building this deeper understanding of the individual at the center of the dispute as a means for more effectively resolving the dispute.

Disputes that arise during non-competent EOL care decisionmaking serve as the context for this paper's discussion of bioethics mediation.⁸ This constitutes a relatively narrow subset of overall caregiving disputes, but presents perhaps the greatest challenge to the dispute resolution process. Section II explores the EOL decisionmaking landscape, including the legal and institutional processes for making EOL decisions and resolving EOL care disputes. This Section further details one particular component to EOL care decisionmaking—the ethics committee.

Section III.A discusses the ethical principles and mediation theory that should form the foundation for bioethics mediation in the EOL care dispute setting. The core ethical principle of autonomy drives the EOL decisionmaking process. But precisely what the exercise of autonomy means in the case of non-competency is challenging. This Section uses Emmanuel Levinas's ethics to respond to the gap between the theoretical exercise of autonomy, which only extends as far as competency, and the practical use of autonomy as a central principle to EOL decisionmaking. Autonomous EOL decisionmaking does not determinatively hinge on a patient's ability to communicate his or her treatment decision. Levinas's ethics of "seeing the face of the other" demands an intimate understanding of the life and essence of a patient. This deeper understanding can serve as an ethical basis for practically recognizing autonomy in the non-competent patient context.

Section III.B proposes a person-centered approach to mediation particularly suited to the EOL care dispute resolution environment. EOL care disputes present unique challenges that do not necessarily fit within traditional mediation theory. Person-centered mediation would apply where the heart of the dispute involves an individual's care or treatment. This approach to mediation recognizes the nature of the decision to be made and the limited choices inherent to such a dispute. It focuses the parties on reaching a resolution that reflects a deeper understanding of the individual at the center of the dispute.

⁸ For purposes of smoother reading, EOL care decisionmaking and similar statements throughout the paper shall refer to non-competent EOL care decisionmaking regardless of whether non-competency is explicitly stated.

Section IV sets forth a model of how this approach to bioethics mediation might work in practice. Bioethics mediation can be formally incorporated into the institutional dispute resolution process. Additionally, bioethics mediation techniques may be taught to the appropriate institutional staff, bringing mediation principles to bear in a more informal manner. In either case, utilizing bioethics mediation may more effectively guide patients and loved ones through the intimate and emotional process of coming to an EOL care decision, and may help prevent decisionmaking disputes from requiring judicial intervention.

II. THE EOL DECISIONMAKING LANDSCAPE

Understanding the process by which EOL decisions are made underscores the benefits of bioethics mediation and the need for a person-centered approach. EOL decisionmaking is a complex affair, mixing patients' legal rights with the perspectives of family, loved ones, medical practitioners, and others. This Section sets forth the current approach to assessing and giving effect to a non-competent patient's wishes, the use and limitations of the judicial process in resolving EOL care disputes when they arise, and the use and limitations of ethics committees in the dispute resolution process.

A. *Protecting Autonomy—Statutory and Common Law Devices*

"In death and dying jurisprudence, the centerpiece . . . is personal autonomy—the almost unassailable right of an individual to make medical treatment decisions even when such decisions result in the accelerated death of the actor."⁹ In response to the jurisprudential focus on autonomy, statutory law has developed to accommodate patients' desires for EOL treatment. All states have enacted legislation allowing patients to execute advanced directives as a means for expressing their wishes regarding EOL care.¹⁰

⁹ Susan Adler Channick, *The Myth of Autonomy at the End-of-Life: Questioning the Paradigm of Rights*, 44 VILL. L. REV. 577, 581 (1999). See also Marshall B. Kapp, *Patient Autonomy in the Age of Consumer-Driven Health Care: Informed Consent and Informed Choice*, 2 J. HEALTH & BIOMED. L. 1, 1 (2006) ("The philosophical principle of individual autonomy, or personal self-determination, lies at the heart of modern American bioethics."); Martin Bienstock, *How We Die: A New Prescription*, 20 J. L. & HEALTH 17, 18 (2006–07) ("[P]ersonal autonomy has been universally acknowledged as the most important value in the end-of-life process").

¹⁰ Thomas L. Hafemeister, *End-of-Life Decision Making, Therapeutic Jurisprudence, and Preventive Law: Hierarchical v. Consensus-Based Decisionmaking Model*, 41 ARIZ. L. REV. 329, 339 (1999). While states formulate the substance of

CONSIDERATIONS IN APPLYING BIOETHICS MEDIATION

Advance directives fall into three general categories: (1) instructional directives ("living wills"); (2) health care proxies ("durable powers of attorney for health care"); and (3) combined directives.¹¹

These different types of advanced directives are documents executed by individuals while still competent, allowing them to make health care decisions before the onset of non-competence.¹² A living will is an instrument "that describes those treatments an individual wishes or does not wish to receive should he or she become incapacitated and unable to communicate treatment decisions."¹³ "Health care proxies allow competent adults to designate surrogate decisionmakers in the event of future incapacity."¹⁴ Combined directives contain both instructional and delegational components; they provide a written expression of the patient's wishes while at the same time naming a health care proxy.¹⁵ These documents are not without their critics,¹⁶ but courts typically uphold their use.¹⁷

In the event that a patient has not expressed his or her intent through a written directive, the common law has developed in a manner that promotes giving effect to patient autonomy.¹⁸ Generally, courts do not view the

advanced directive statutes, through the Patient Self-Determination Act, 42 U.S.C. § 1395cc (1990), the federal government ensures patients have a right to formulate advance directives and allows patients the right to accept or refuse treatment. *See id.* *See also* GEORGE D. POZGAR, *LEGAL AND ETHICAL ISSUES FOR HEALTH PROFESSIONALS* 105 (2005); Karen A. Butler, *Harvesters: Alternatives to Judicial Intervention in Medical Treatment Decisions*, 1996 J. DISP. RESOL. 191, 197.

¹¹ T. P. Gallanis, *Write and Wrong, Rethinking the Way We Communicate Health-Care Decisions*, 31 CONN. L. REV. 1015, 1018–19 (1999).

¹² POZGAR, *supra* note 10, at 107. *See also* Gallanis, *supra* note 11, at 1025.

¹³ POZGAR, *supra* note 10, at 107.

¹⁴ Gallanis, *supra* note 11, at 1029. *See also*, POZGAR, *supra* note 10, at 109.

¹⁵ Gallanis, *supra* note 11, at 1029.

¹⁶ Gallanis identifies four uncertainties associated with instructional directives: uncertainty of preparation, uncertainty of execution, uncertainty of revocation, and uncertainty of interpretation. *Id.* at 1026–29. He posits that health care proxies share the first three uncertainties, but instead of an uncertainty in interpretation, health care proxies are subject to uncertainty of agent location. *Id.* at 1030–31.

¹⁷ Hafemeister, *supra* note 10, at 339.

¹⁸ The two frequently cited cases demonstrative of this development are *In re Quinlan* and *Cruzan*. *In re Quinlan*, 70 N.J. 10 (1976), *cert. denied sub nom* Garger v. New Jersey, 429 U.S. 922 (1976); *Cruzan v. Director, Missouri Department of Health*, 497 U.S. 261 (1989). The *Cruzan* Court recognized a liberty interest in an individual's right to refuse medical treatment, stating that "[t]he principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions." *Id.* at 278. One particularly notable aspect of the

absence of an advanced directive as an end to the decisionmaking process, but instead look to a surrogate decisionmaker to consider EOL options as a proxy for the patient.¹⁹ Surrogate decisionmakers commonly engage in one of two modes of analysis—substituted judgment or best interest.²⁰

Under the substituted judgment standard, surrogates "attempt to extrapolate what patients would have decided about a specific medical treatment, if they had the capacity to do so, from any evidence indicating the wishes of patients regarding medical decisions expressed before patients lost capacity."²¹ If a patient's intent is not evident, the surrogate may turn to a best interest analysis, whereby the surrogate makes an objective assessment of the course of treatment that is in the best interest of the patient.²² Both these approaches respect patient autonomy by attempting to fulfill the desires or needs of the patient.²³

Quinlan decision is the court's reliance on the hospital ethics committee in evaluating the propriety of an EOL care decision. The court stated:

Upon the concurrence of the guardian and family of Karen, should the responsible attending physicians conclude that there is no reasonable possibility of Karen's ever emerging from her present comatose condition to a cognitive, sapient state and that the life-support apparatus now being administered to Karen should be discontinued, they shall consult with the hospital "Ethics Committee" or like body of the institution in which Karen is then hospitalized. *If that consultative body agrees that there is no reasonable possibility of Karen's ever emerging from her present comatose condition to a cognitive, sapient state, the present life-support system may be withdrawn and said action shall be without any civil or criminal liability therefor on the part of any participant, whether guardian, physician, hospital or others.*

Quinlan, 70 N.J. at 54 (emphasis added).

¹⁹ Hafemeister, *supra* note 10, at 339–40.

²⁰ Butler, *supra* note 10, at 198–200. See also Norman L. Cantor, *Twenty-Five Years after Quinlan: A Review of the Jurisprudence of Death and Dying*, 26 J. L. MED. & ETHICS 182 (2001).

²¹ Butler, *supra* note 10, at 198.

²² *Id.* at 200.

²³ Of note, best interest analysis is the one component of the decisionmaking process that formally breaks from strictly giving effect to patient autonomy. While autonomy may factor in, it is only a part of the broader objective assessment of the proper course of treatment. Still, the vast majority of the decisionmaking process centers on patient autonomy.

CONSIDERATIONS IN APPLYING BIOETHICS MEDIATION

B. *The Prominent Role of the Ethics Committee*

Though EOL decisionmaking is arguably hierarchical in nature²⁴ (with either the patient or surrogate at the top of the hierarchy), other actors may substantially influence the decision rendered. Historically, courts avoided intervening in EOL care decisions, but in recent years they have increased their involvement at the behest of physicians and families.²⁵ In conjunction with the rise of judicial intervention, ethics committees have taken on increased importance as well.²⁶ Ethics committees have become an important vehicle for a hospital's ethical views and, consequently, an important avenue for introducing mediative techniques in an effort to effectively resolve disputes at the institutional level. Even further, an analysis of the limitations of ethics committees strongly justifies implementing bioethics mediation prior to committee involvement in the dispute resolution process.

Ethics committees reflect diverse perspectives that may have a substantial impact on EOL decisionmaking. Ethics committees typically consist of an interdisciplinary mix of members that may include physicians, nurses, hospital administrators, ethicists, clergy, and lawyers, as well as business, community, and political leaders.²⁷ While ethics committees have a variety of roles,²⁸ most germane to EOL decisionmaking is their role in consultation and conflict resolution. A surrogate decisionmaker may request an ethics consultation to aid in coming to a determination regarding care or to help resolve a dispute over the proper course of treatment.²⁹ Ultimately, the

²⁴ See Hafemeister, *supra* note 10, at 337–43. Hafemeister rejects the hierarchical approach and instead advocates for a consensus-based approach to EOL decisionmaking. He states, "[a]n exclusive focus on patient autonomy can be insensitive to the harm it causes the family, overlook relevant family dynamics and the needs of the family and the patient, undercut the principles of beneficence and justice, and be unachievable for patients who lack decisionmaking capacity." *Id.* at 358.

²⁵ Butler, *supra* note 10, at 192. While *Quinlan* is largely attributed with the rapid increase in hospitals' use of ethics committees, other observers have noted the impact of changes in medical technology. For example, John Oldershaw observed that one early stimulus for ethics committees was the development and use of the kidney dialysis machine, which forced institutions to select and reject patients for treatment due to the limited availability of dialysis. John B. Oldershaw, *Persistent Vegetative State: Medical, Ethical, Religious, Economic and Legal Perspectives*, 1 DEPAUL J. HEALTH CARE L. 495, 516 (1997).

²⁶ See *Quinlan*, *supra* note 18.

²⁷ Hoffman, *supra* note 4, at 822. See also POZGAR, *supra* note 10, at 74.

²⁸ These roles include directing educational programs and developing policy and procedures. Butler, *supra* note 10, at 206.

²⁹ See Hoffman, *supra* note 4, at 822–23.

opinion of an ethics committee may be given great weight in deciding the proper course of EOL care.³⁰

In coming to a decision, an ethics committee takes into consideration a range of factors.³¹ In describing a formal consultation, one practitioner's manual states that the ethics committee should:

1. Identify the ethical dilemma, i.e., reasons why the consult was requested.
2. Identify relevant facts.
 - a. diagnosis and prognosis
 - b. patient goals and wishes
 - c. regulatory and legal issues
 - d. professional standards and codes of ethics
 - e. institutional policies and values
3. Identify the stakeholders.
4. Identify moral issues.
 - a. human dignity
 - b. common good
 - c. justice
 - d. beneficence
 - e. respect for autonomy
 - f. informed consent
 - g. medical futility, among others
5. Identify legal issues.
6. Consider alternative options.
7. Conduct consultation.
 - a. review, discuss, and provide reasoning for recommendations made.
8. Review and follow up.

³⁰ See *Quinlan*, *supra* note 18. See also Bethany Spielman, *Has Faith in Health Care Ethics Consultants Gone too Far? Risks of an Unregulated Practice and a Model Act to Contain Them*, 85 MARQ. L. REV. 161 (2001). Spielman extensively explores the legal status of ethics consultation. *Id.* at 161–79. She notes that in some states, ethics committees may act as a patient's surrogate or courts may consider an ethics committee's decision in a dispute to be final. *Id.* at 173–74.

³¹ POZGAR, *supra* note 10, at 76–77 (identifying such factors as including: the patient's current medical status, diagnosis, and prognosis; the benefits and burdens of the recommended treatment or alternative treatments; the effect(s) of no treatment; the life expectancy, treated and untreated; the views of caregivers and consultants; pain and suffering; quality of life issues; and the financial burden on family).

CONSIDERATIONS IN APPLYING BIOETHICS MEDIATION

9. Committee discussion should include family members once the committee has had an opportunity to review the request for consultation.
10. Family members should be asked what their hopes and expectations are.³²

The consultation process appears to capture a range of considerations, but questions remain as to whether, practically speaking, the committee actually functions in this manner.

Ethics committees have been subject to criticism in that their composition and practice do not adequately address the interests of the patient. Although arguably multidisciplinary, ethics committees typically consist of a homogenous membership—generally Caucasian, middle-to-upper class individuals with college or advanced degrees.³³ Such a membership may not share similar values as the patient community whom it serves, which could lead to an opinion that does not adequately take into account the personal values of a particular patient.³⁴ A deeper problem with the committee membership is that, more often than not, the majority of the ethics committee members are in some way associated with the health care institution in which the patient receives care.³⁵

An ethics committee's strong association with the health care provider raises the possibility of a conflict of interest in its involvement with the dispute resolution process, as committees purportedly acting on behalf of the patient also have a vested interest in the needs of the health care institution for which they serve. The potential for a conflict of interest is particularly evident where the expressed desires of the patient differ from the course of treatment recommended by the health care provider. In such an instance, the ties between the ethics committee and the institution may result in increased pressure on the committee to focus on liability considerations, as the health care provider has a strong interest in mitigating the risk of litigation.³⁶

An additional conflict of interest arises from the commitment ethics committee members may have to particular ethical positions. Institutional policy or personal belief may lead to the ethics committee or consultant

³² *Id.* at 79.

³³ Butler, *supra* note 10, at 205.

³⁴ *Id.* Butler notes studies that have indicated that race, education, religious beliefs, and age may impact individuals' beliefs regarding whether a person's life should always be saved. *Id.* at 205–06.

³⁵ *Id.* at 205.

³⁶ *Id.* at 189–90. *See generally infra* note 51.

having a firm belief about the viability of a particular ethical decision.³⁷ A hospital may have an institutional policy dictating that the ethics committee should make decisions that avoid legal liability.³⁸ Individual committee members may hold a personal belief about whether a family member could ever override a patient's advance directive.³⁹ However, these policies or beliefs may be the very focus of the disagreement requiring the attention of the ethics committee.⁴⁰ In such circumstances, the voracity with which an ethics committee member holds on to a particular personal belief may result in a conflict of interest in handling a specific case.⁴¹

EOL decisions take place amidst a complex legal backdrop with a range of interested parties. Courts are ill-suited forums for rendering decisions of such an intimate nature.⁴² Adjudication lengthens the decisionmaking process due to the slow-paced nature of litigation and the potential for appeal.⁴³ Further, the adjudicatory process might not adequately address value-oriented conflicts and may have difficulty balancing the myriad interests and parties before the court in an EOL care dispute.⁴⁴ Ethics committees offer increased flexibility and sensitivity to these difficult decisions, but may be subject to bias and conflicts of interests. So, how might these disputes best be resolved?

³⁷ Spielman, *supra* note 30, at 187.

³⁸ George J. Annas, *Ethics Committees in Neonatal Care: Substantive Protection or Procedural Diversion?*, 74 AM. J. PUB. HEALTH 843, 843 (1984) ("Institutions and their staffs often see the primary function of ethics committees as protecting them against potential legal liability for treating or not treating particular patients.").

³⁹ Spielman, *supra* note 30, at 187. Spielman also references the scenario where an individual member has a personal belief as to the conditions necessary for a family member to have the capability to refuse EOL treatment for a patient lacking an advance directive. *Id.* One can easily imagine other important personally held beliefs coming to bear in this setting, such as views on the sanctity of life, quality of life, whether it is ever appropriate to remove treatment, or other moral or religious beliefs.

⁴⁰ *Id.*

⁴¹ For example, the tension between paternalism and patient autonomy. See Ben A. Rich, *Medical Paternalism v. Respect for Patient Autonomy: The More Things Change the More They Remain the Same*, 10 MICH. ST. J. MED. & LAW 87 (2006).

⁴² Hafemeister, *supra* note 10, at 337 n.60.

⁴³ I. Glenn Cohen, *supra* note 4, at 284.

⁴⁴ *Id.* at 287–93, 308–09.

CONSIDERATIONS IN APPLYING BIOETHICS MEDIATION

III. TOWARDS A NEW MODEL OF PERSON-CENTERED MEDIATION

Bioethics mediation presents a compelling option to aid in addressing the diverse interests inherent to EOL disputes while maintaining the patient's autonomy in reaching a decision. Resolving EOL care disputes involves a variety of parties and interests—a reality better handled by mediation than the adjudicatory process. Further, mediation can effectively keep the focus of the dispute on the patient and away from other biases or motives. However, fully realizing the potential of bioethics mediation in this setting requires a deeper examination of the exercise of autonomy and the theory of mediation.

A. Rethinking Autonomy: Applying Levinas to the Autonomy Gap

Autonomy has evolved into the core value and philosophical principle of modern American bioethics.⁴⁵ However, the ethical principle of autonomy is in a sense outpaced by the practical use of autonomy in EOL decisionmaking. While from a theoretical perspective autonomy is limited by competency, the practical exercise of autonomy remains the focus of the EOL decisionmaking, regardless of competency—thus forming an autonomy gap between theory and practice. Adding further difficulty, the nature of the EOL decisionmaking process can complicate determinations of autonomy as the patient is often lost amidst the landscape of competing medical, ethical, community, and personal principles, all of which can be exacerbated in the instance of a dispute. Returning the focus to patient autonomy in EOL decisionmaking and dispute resolution requires rethinking and expanding the ethical idea of autonomy to meet the needs of the practical exercise of this principle. Emmanuel Levinas, the 20th century French philosopher, provides a construction of ethics which does just that.

1. The Meaning and Challenges of Autonomy—Theory vs. Practice

Over the course of the last century, autonomy has come to the forefront of bioethics theory.⁴⁶ Bioethics can be conceived of as having four core

⁴⁵ Kapp, *supra* note 9, at 1 ("The philosophical principle of individual autonomy, or personal self-determination, lies at the heart of modern American bioethics."). See generally *supra* note 9.

⁴⁶ Bienstock, *supra* note 9, at 18 ("In the thirty years since the seminal *In re Quinlan* case, personal autonomy has been universally acknowledged as the most important value in the end-of-life process."); Alan Meisel, *Managed Care, Autonomy, and Decisionmaking at the End of Life*, 35 Hous. L. Rev. 1393, 1397 (1999) ("The greatest

principles: (1) autonomy, (2) nonmaleficence, (3) beneficence, and (4) justice.⁴⁷ While nonmaleficence and beneficence have played prominent historical roles, autonomy and justice have more recently risen to greater prominence.⁴⁸ One can certainly argue the propriety of autonomy as the priority principle of bioethics,⁴⁹ but the fact remains that the legal and decisionmaking processes have evolved to give effect to this right.⁵⁰

Autonomy can be a difficult principle to precisely define.⁵¹ Literally translated, "autonomy means living by a law that one imposes on oneself or, in other words, the right to live one's own life in one's own way."⁵² Autonomy recognizes the human capacity for self-determination.⁵³ As

revolution of twentieth century American society has been the assertion of citizen autonomy.").

⁴⁷ TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 38 (4th ed. 1994). More specifically, the authors describe these "four clusters of principles" in more detail as "(1) respect for autonomy (a norm of respecting the decisionmaking capacities of autonomous persons), (2) nonmaleficence (a norm of avoiding the causation of harm), (3) beneficence (a group of norms for providing benefits and balancing benefits against risk and costs), and (4) justice (a group of norms for distributing benefits, risks, and costs fairly)." *Id.*

⁴⁸ *Id.*

⁴⁹ Hoffman, *supra* note 4, at 859 ("While mediation is designed to promote the autonomy of the parties to the dispute, it is not clear that this is or should be the goal of ethics committees. Patient protection must be at the forefront of committee concerns."); Hafemeister, *supra* note 10, at 329–30 (arguing that decisionmaking should shift from a single-decider hierarchical structure to a consensus-based approach); Martha Minow, *Trends in Health Care Decisionmaking: Who's the Patient?*, 53 MD. L. REV. 1173, 1173 (1994) ("What can and what should autonomy of the individual patient mean in light of the relationships with others that can be crucial in preventing, diagnosing, treating, and managing health conditions?").

⁵⁰ See *supra* Part II. At least one commentator has questioned whether this is in fact the case, or whether autonomy-driven decisionmaking is only a myth. See Channick, *supra* note 9.

⁵¹ See BEAUCHAMP & CHILDRESS, *supra* note 47, at 120. The authors note that autonomy "has acquired meanings as diverse as self-governance, liberty rights, privacy, individual choice, freedom of the will, causing one's behavior, and being one's own person." *Id.*

⁵² Channick, *supra* note 9, at 585. Channick continues, "[p]erhaps the most important current conceptualization of autonomy is autonomy as a negative liberty interest establishing a zone of privacy and noninterference around each person." *Id.* at 585–86.

⁵³ Noel Tiano & Elizabeth Beyer, *Cultural and Religious Views on Nonbeneficial Treatment*, in *ETHICAL DILEMMAS AT THE END OF LIFE* 41, 43 (Kenneth J. Doka et al. eds., 2005), quoting Miller, *Autonomy*, *ENCYCLOPEDIA OF BIOETHICS* 246, 246 (3d ed. 2004). William M. Lamers goes on to note important attributes of autonomy, stating:

CONSIDERATIONS IN APPLYING BIOETHICS MEDIATION

applied in the medical context, "patient autonomy can be translated as the ethical principle that preserves an individual's ability to make and carry out informed decisions that arise from unbiased and thoughtful deliberation."⁵⁴

Competency plays a key role in patient autonomy. An autonomous action is one taken: "(1) intentionally, (2) with understanding, and (3) without controlling influences that determine [the] action."⁵⁵ Competency depends on whether a patient has the capacity "to understand . . . material information, to make a judgment about the information . . . , to intend a certain outcome," and freely communicate this decision.⁵⁶ Thus, autonomy and competency are inextricably linked—an autonomous person is one who is competent to make a decision and a determination of competency involves a consideration of whether a person is autonomous.⁵⁷

Autonomy presents a particular challenge in the EOL care context. EOL care conflicts fall within a legal regime that is structured to give effect to patient autonomy.⁵⁸ A competent patient most commonly exercises his or her autonomy by means of granting informed consent.⁵⁹ However, autonomy in the non-competent EOL care context is complicated in part by a theoretical perspective that demands competency as a prerequisite for the exercise of autonomy. Advanced directives may somewhat resolve the issue. A patient may create an advanced directive while competent to express a desired treatment decision for a situation that may arise where the patient is non-competent. But where the advanced directive is unclear or the patient has

Autonomy is a fundamental right that enables us to be treated as individuals rather than as numbers or part of a collective. Autonomy makes us "real." Autonomy makes it possible for us to speak out, affirms our right to choose what happens to us, and allows us to be represented as persons of interest; persons with needs, a past, a present, and a future. The concept of autonomy empowers us to make informed treatment decisions that are consistent with our culture, our values, and our belief systems.

William M. Lamers, Jr., *Autonomy, Consent, and Advance Directives*, in *ETHICAL DILEMMAS AT THE END OF LIFE* 105, 110 (2005).

⁵⁴ See Jamie S. King & Benjamin W. Moulton, *Rethinking Informed Consent: The Case for Shared Medical Decisionmaking*, 32 AM. J. L. & MED. 429, 435 (2006).

⁵⁵ BEAUCHAMP & CHILDRESS, *supra* note 47, at 123.

⁵⁶ *Id.* at 135.

⁵⁷ *Id.*

⁵⁸ See *infra* Part III

⁵⁹ See BEAUCHAMP & CHILDRESS, *supra* note 47, at 133. ("This ethical precept [autonomy] has been transformed slowly but steadily in the United States into the enforceable legal doctrine of informed consent, reflecting the phenomenon that 'the law is society's mechanism for establishing boundaries for conduct.'"). See also King & Moulton, *supra* note 54, at 434–37 (2006).

provided no prior guidance, giving effect to patient autonomy in a practical sense departs from what is possible of autonomy from a theoretical sense.⁶⁰

2. Bridging the Gap—Levinas's "Seeing the Face of the Other"

Ethics can and must respond to the challenge of giving effect to a non-competent patient's autonomy. A gap exists between the legal regime of autonomy and the extent of autonomy ethics. The legal regime places autonomy as the basis for all decisionmaking, but as an ethical principle, autonomy would not be present for non-competent decisionmakers. So long as the legal regime governing medical decisionmaking places patient autonomy at the forefront, ethics must build on the concept of autonomy to meet the legal needs of the non-competent patient. Emmanuel Levinas's ethical concepts can respond to the need for addressing autonomy in the EOL context.

Levinas views ethical conduct in terms of "seeing the face of the other,"⁶¹ a conceptualization that transforms ethics into a deep focus on understanding the human, i.e., patient, condition.⁶² For Levinas, "ethical life begins when we can escape the centrifugal pull of our own identities, needs, interests, and values, and plot a new trajectory toward others."⁶³ To accomplish this, one must experience the face of the other.

"Seeing the face of the other" roots ethics in a deep understanding of the conditions of those around us. For Levinas, "[t]he face is an irreducible mode in which a being can present itself in its identity"⁶⁴ and the means by which

⁶⁰ Channick, *supra* note 9, at 587 ("Because independence and self-reliance are crucial aspects of autonomy, competency is a predicate to the exercise of autonomy.").

⁶¹ See generally EMMANUEL LEVINAS, *TIME AND THE OTHER* (Richard A. Cohen trans., 1987).

⁶² This paper by no means endeavors to fully define Levinas's ethical metaphysics, a term first coined by Edith Wyschogrod, in EMMANUEL LEVINAS: *THE PROBLEM OF ETHICAL METAPHYSICS* (1974). Such an exploration is far outside the scope of this paper and several authors have explored Levinas's work. See generally SILVIA BENSO, *THE FACE OF THINGS: A DIFFERENT SIDE OF ETHICS* (2000); JOHN LLEWELYN, *EMMANUEL LEVINAS: THE GENEALOGY OF ETHICS* (1995); MICHAEL B. SMITH, *TOWARD THE OUTSIDE: CONCEPTS AND THEMES IN EMMANUEL LEVINAS* (2005); ELISABETH LOUISE THOMAS, *EMMANUEL LEVINAS: ETHICS, JUSTICE, AND THE HUMAN BEYOND BEING* (2004). Instead, this paper narrowly focuses on Levinas's views of human relationships as mechanisms for defining an ethical existence.

⁶³ Kathleen Marie Dixon, *The Quality of Mercy: Reflections on Provider-Assisted Suicide*, J. CLINICAL ETHICS 290, 291 (Fall 1997).

⁶⁴ BENSO, *supra* note 62, at 31, quoting EMMANUEL LEVINAS, *DIFFICILE LIBERTÉ. ESSAIS SUR LE JUDAÏSME* 20 (1963). See also EMMANUEL LEVINAS, *ETHICS AND INFINITY*:

CONSIDERATIONS IN APPLYING BIOETHICS MEDIATION

one experiences the other.⁶⁵ Encountering the face of the other is a transcendent experience that awakens one's sense of being human by exposure to the human essence of another.⁶⁶ The defining aspect of this transcendent moment is one's exposure to the vulnerability of another.

Levinas' ethical construction defines our collective experience in relation to the vulnerability of others. As one commentator explains:

It is when I see that the other is a person who can be hurt, distressed, pained, suffering, anguished, weak, in grief, or in despair that I may be opened to the essential being of the other. The vulnerability of the other is the weak spot in the armor of the self-centered world. I see a person who is hurt or who is in agony and, temporarily at least, I forget my present preoccupations. No longer am I driven by my personal agenda. For the moment I am just there for this child, man, or woman. With this recognition of the other comes the possibility of acting for the sake of the other. And so when a person is ill and I actually "see" this person in his or her vulnerability then I am temporarily lifted over the boundary-chasm of self-centeredness that separates me from experiencing the other as other. This then, says Levinas, is the experience of unselfishness, of responsibility by and for the other.⁶⁷

Exposing oneself to the vulnerability of another is a transcendent experience by which one defines his or her own ethical existence.⁶⁸ Levinas advocates a responsibility for the other not grounded in any sort of contractual relation or categorical duty, but that of love and moral

CONVERSATIONS WITH PHILIPPE NEMO 86 (Richard A. Cohen trans., 1985) ("The face is signification, and signification without context. I mean that the Other, in the rectitude of his face, is not a character within a context . . . Here, to the contrary, the face is meaning all by itself. You are you. In this sense one can say that the face is not 'seen.' It is what cannot become a content, which your thought would embrace; it is uncontainable, it leads you beyond." *Id.* at 86.)

⁶⁵ EMMANUEL LEVINAS, *TOTALITY AND INFINITY: AN ESSAY ON EXTERIORITY* 50 (A. Lingis trans., 1969) ("To the question 'who is the Other?' one should thus respond: *Autrui* [other] is face, where 'face' names 'the way in which the other presents himself exceeding the idea of the other in me'").

⁶⁶ RICHARD A. COHEN, *EMMANUEL LEVINAS: HUMANISM OF THE OTHER* vii, xxvi–xxvii (Nidra Poller trans., 2003). See also BENSO, *supra* note 62, at 25; THOMAS, *supra* note 62, at 2 ("What first awakens the sense of the human is an encounter with the Other.").

⁶⁷ Dixon, *supra* note 63, at 291.

⁶⁸ Absent an experience of the other, one remains in a state of "self-love, self-satisfaction, and self-relation" whereby one "complacently returns to itself, overlooking, ignoring, neglecting, abandoning, escaping, and otherwise refusing the priority of its moral responsibility to and for the other person." COHEN, *supra* note 66, at xxvii.

responsibility based on the "superlative moral priority of the other person."⁶⁹ In Levinas's eyes, "the dignity of the self arises in and as an unsurpassable moral responsibility to and for the other person . . . [a]nd moral responsibility for the one who faces leads to the demand for justice for all those who do not face, for all others, all humanity."⁷⁰

Ultimately, through experiencing the face of the other, Levinas advances a construction of ethics with a core value of being for the other as first priority. In describing his work, Levinas states:

I have attempted a "phenomenology" of sociality starting from the face of the other person—from proximity—by understanding in its rectitude a voice that commands before all mimicry and verbal expression, in the mortality of the face, from the bottom of this weakness. It commands me to not remain indifferent to this death, to not let the Other die alone, that is, to answer for the life of the other person, at the risk of becoming an accomplice in that person's death.⁷¹

Levinas' patient-focused ethical construction comports well with the demands of EOL care decisions.

Levinas's ethics can address the need for determining a non-competent patient's EOL treatment decisions in a manner consistent with the exercise of patient autonomy. As previously discussed, giving effect to patient autonomy lies at the heart of EOL care decisionmaking and health care in general.⁷² However, practically speaking, the decisionmaking process has been broadened by the influence of numerous interests and actors, effectively shifting the focus away from where it should properly fall—on the life and needs of the patient.

Levinas's ethics provides a framework for returning to a patient-centered autonomy ethic for the non-competent patient. "Seeing the face of the other" requires one to intimately understand the life and condition of the patient. It depends less on external actors and principles and more on a deeper meaning

⁶⁹ COHEN, *supra* note 66, at xxvi. See also Dixon, *supra* note 63, at 291.

⁷⁰ COHEN, *supra* note 66, at xxvi. See also LEVINAS, ETHICS AND INFINITY, *supra* note 64, at 89 ("There is a commandment in the appearance of the face, as if a master spoke to me. However, at the same time, the face of the Other is destitute; it is the poor for whom I can do all and to whom I owe all. And me, whoever I may be, but as a 'first person,' I am he who finds the resources to respond to the call.").

⁷¹ Dixon, *supra* note 63, at 291, quoting EMMANUEL LEVINAS, TIME AND THE OTHER 109 (Richard A. Cohen trans., 1987).

⁷² Lamers, *supra* note 53 (Lamers quotes the revised Code of Ethics of the American Medical Association, which states that "[p]hysicians have an obligation to relieve pain and suffering and to promote the dignity and autonomy of dying patients in their care.").

CONSIDERATIONS IN APPLYING BIOETHICS MEDIATION

and understanding of the patient as a person.⁷³ In the non-competent patient context, ethical decisions must be made with a full appreciation for the essence of the patient before such a decision could at least arguably comport with the goal of giving effect to the patient's autonomous wishes.

The decisionmaking process, both internal to the hospital and the external adjudicatory process, needs to build an understanding of the patient's life before rendering advice or a decision on the EOL treatment of a non-competent patient.⁷⁴ This understanding of the essence of another makes up the core of Levinas's ethics and can fill the gap between the limit of autonomy as an ethical principle and the use of autonomy as the driving ideal for the decisionmaking process. However, recognizing an extension of ethics and autonomy does not in and of itself translate to an influence on the decisionmaking process. Mediation and mediation techniques can bring a patient-centered ethics to bear on EOL care decisionmaking.

B. The Person-Centered Mediation Approach

Using mediation to incorporate a deeper understanding of the patient in EOL care disputes requires an evaluation of the theory of mediation that would serve as the foundation to this approach. In a general sense, mediation is understood as "an informal process in which a neutral third party with no power to impose a resolution helps the disputing parties try to reach a mutually acceptable settlement."⁷⁵ This foundation still applies in the context

⁷³ Certainly there is a strong theological component to Levinas's views. See LEVINAS, ETHICS AND INFINITY, *supra* note 64, at 92 ("In the access to the face there is certainly also an access to the idea of God."). See generally EMMANUEL LEVINAS, DIFFICULT FREEDOM: ESSAYS ON JUDAISM (Seán Hand trans., 1990); EMMANUEL LEVINAS, GOD, DEATH, AND TIME (Bettina Bergo trans., 2000). In some sense, "seeing the face of the other," as a transcendent experience, is almost like building a spiritual connection between oneself and the person before them.

⁷⁴ Interestingly (and anecdotally), this component seemed lacking in the debate over the treatment of Terri Schiavo. More often than not, the media presented pictures of Terri in her present state—debilitated by effects of her Persistent Vegetative State (PVS)—rather than pictures of her vibrantly living her life before the PVS took hold. This gives the impression of a present moment focus, rather than a more robust consideration of her life and who she was.

⁷⁵ ROBERT A. BARUCH BUSH AND JOSEPH P. FOLGER, THE PROMISE OF MEDIATION: RESPONDING TO CONFLICT THROUGH EMPOWERMENT AND RECOGNITION 2 (1994). This section draws heavily on Bush's and Folger's view of mediation as a transformative process. See also SUSAN STEWART, CONFLICT RESOLUTION: A FOUNDATION GUIDE (1998); EDWARD W. SCHWERIN, MEDIATION, CITIZEN EMPOWERMENT, AND TRANSFORMATIONAL POLITICS 7 (1995).

of EOL decisionmaking—the ultimate result is that disputing parties reach a decision with regard to treatment. But the nature of EOL care disputes requires different thinking with regard to the appropriate goal of mediation. In resolving EOL care disputes, the goal of mediation should be building a robust conception of the patient and the situation in a manner that allows the disputants to reach a decision tantamount to giving effect to what this conception of the patient would reveal to be his or her autonomous wishes.⁷⁶ This mediation process may be aptly termed person-centered mediation.

1. *Bush and Folger as the First Step to a Person-Centered Approach*

Transformative mediation provides a starting point for the person-centered mediation approach. Bush and Folger describe this approach to mediation as a means to "transform the character of both individual disputants and society as a whole."⁷⁷ The transformative approach uses mediation as a tool to create social value from conflict. Allowing parties to create mutually acceptable resolutions to their disputes contributes value in the sense of enhancing party satisfaction and lessening the strain on the judicial system. Mediation can also create value as a means of transforming conflict into a way for parties to not only resolve their dispute, but to

⁷⁶ Other commentators have posited different goals and justifications for using mediation to resolve EOL care disputes, including physician-patient trust and the benefit of enhanced development of mediation standards in contrast to those of the ethics committee. Gatter, *supra* note 4, at 1098. "[T]he value of preserving patients' trust in their physicians at the end-of-life justifies a policy of using mediation to resolve physician-patient EOLT disputes." *Id.*

⁷⁷ BUSH & FOLGER, *supra* note 75, at 20. Bush and Folger identify four perspectives on mediation: satisfaction, social justice, oppression, and transformation. *Id.* at 15–23. This paper discusses the transformative perspective at length. Satisfaction embodies the idea that the flexibility, informality, and consensus-building nature of mediation helps facilitate collaborative and integrative problem solving, resulting in the process of mediation as a powerful tool to producing quality resolutions to individual disputes. *Id.* at 16. The social justice perspective approaches mediation as a way to identify and organize otherwise adversarial individuals around common interests as a means to building stronger community bonds and structures. Social justice may be achieved by organizing unaffiliated individuals around common interests, giving them greater leverage in reaching a resolution to a dispute. *Id.* at 18. The oppression perspective takes the opposite tact, positing that the informality and consensuality of mediation (and the lack of procedural and substantive rules) lends the process to heightened power imbalances and exploitation by a stronger party, with the mediator being hindered by neutrality in attempting to remedy these discrepancies. *Id.* at 22.

CONSIDERATIONS IN APPLYING BIOETHICS MEDIATION

understand themselves as individuals and to relate to one another.⁷⁸ Focusing on the transformative value of mediation is not to say that achieving mutually acceptable settlement is insignificant, but instead prioritizes the ability of mediation to build strength and compassion via stimulating moral growth over other goals.⁷⁹ To accomplish this moral growth, transformative mediation focuses on two objectives: empowerment and recognition.⁸⁰

Empowerment and recognition constitute the areas of personal moral growth that transformative mediation seeks to engender amongst the participating parties. While success in problem-solving mediation is defined by improving the parties' situation, transformative mediation seeks to improve the parties themselves.⁸¹ Empowerment gives a party a sense of strength and control over their situation.⁸² In the context of mediation, parties are empowered when "they grow calmer, clearer, more confident, more organized, and more decisive."⁸³ As a result, through mediation the party gains a greater sense of self-worth, security, self-determination, and autonomy.⁸⁴ Turning to recognition, conflict lends itself toward self-protecting behavior. Recognition occurs when a party expands his or her perspective to incorporate an appreciation for another individual's situation.⁸⁵ This occurs in mediation when parties "voluntarily choose to become more open, attentive, sympathetic, and responsive to the situation of the other party."⁸⁶ Through recognition, a party enhances his or her capacity to acknowledge and understand the concerns of others, realizing the ability to move beyond one's self and appreciate an experience of common humanity.⁸⁷ Empowerment and recognition in mediation are the building blocks for moral growth of the parties involved—growth that creates social value.⁸⁸

⁷⁸ BUSH & FOLGER, *supra* note 75, at 4. "Mediation was appealing not because resolution or settlement was good in itself and conflict evil, but because of the way in which mediation allowed disputing parties to understand themselves and relate to one another *through and within conflict*." *Id.*

⁷⁹ *Id.* at 28–29.

⁸⁰ *Id.* at 84.

⁸¹ *Id.*

⁸² *Id.* at 85.

⁸³ BUSH & FOLGER, *supra* note 75, at 85.

⁸⁴ *Id.* at 87.

⁸⁵ *Id.* at 89.

⁸⁶ *Id.*

⁸⁷ *Id.* at 91.

⁸⁸ BUSH & FOLGER, *supra* note 75, at 94–95. Bush and Folger describe the ultimate aim of transformative mediation as follows:

Person-centered mediation builds on the ideas of empowerment and recognition inherent to transformative mediation, but shifts the focus of these principles from the parties to the person at the center of the dispute. Particular aspects of the transformative approach do not quite fit within the context of EOL care dispute resolution. Fostering the moral growth of the parties to the dispute should benefit resolution to an EOL care dispute. However, the private, intimate nature of these disputes does not necessarily comport with the ideal of imparting broad social change.⁸⁹ Additionally, too much of a focus on empowering the parties in such a value-laden environment might cause them to entrench, leading to the very type of prolonged dispute that mediation seeks to avoid.

2. *A New Approach: Person-Centered Mediation*

Person-centered mediation serves as a method to address intimate, value-focused disputes involving the treatment of another. As implied by the preceding sentence, person-centered mediation applies in situations where the dispute involves the treatment or care of a person. While this applies to EOL care disputes, it also encompasses child care and custody disputes, elder care disputes, and other similar circumstances. These types of disputes share common characteristics, including: (1) a decision made as to the care of another, (2) a limited set of outcomes for the decision, (3) decisions of a value-oriented nature, and (4) a mix of familiar and institutional parties.

Transformation is a different *kind* of goal. It involves changing not just situations but people themselves, and thus the society as a whole. It aims at creating "a better world," not just in the sense of a more smoothly or fairly working version of what now exists but in the sense of a different kind of world altogether. The goal is a world in which people are not just better off but better: more human and more humane. Achieving this goal means transforming people from dependent beings concerned only with themselves (weak and selfish people) into secure and self-reliant beings willing to be concerned with and responsive to others (strong and caring people). The occurrence of this transformation brings out the intrinsic good, the highest level, within human beings. And with changed, better human beings, society as a whole becomes a changed, better place.

Id. at 29.

⁸⁹ Bush and Folger speak of social change as a derivative of the positive change in the individuals who participate in mediation. *Id.* at 29. However, in light of the intensely private nature of an EOL dispute, the notion of broad social change might not be an appropriate component of the mediation process. Given what is essentially a life-or-death decision, mediation should remain intensely focused on the significance of the decision and the parties who are forced to reach a resolution. Social change could be an incremental benefit, but only ancillary to the mediation process.

CONSIDERATIONS IN APPLYING BIOETHICS MEDIATION

The limited range of outcomes challenges a traditional benefit associated with mediation. As commonly understood, mediation seeks to improve parties' positions by expanding the range of possible resolutions to a dispute—i.e., finding success via a better outcome. However, not all disputes comport with the standard model. In some instances, the possible outcomes to a dispute may be severely limited, essentially eliminating the possibility of creating value through creative or expanded resolution.⁹⁰ In these circumstances, mediation must adapt to conform to the limited possible outcomes.

Given the limited outcomes and personal focus, a critical component to person-centered mediation is defining the decision to be made. The decision must be defined to acknowledge the limits on the outcomes but keep the focus on the individual. Take an EOL care dispute as an example. The outcomes of the dispute are essentially a binary decision as to whether to continue treatment to prolong the life of the patient or to withdraw treatment to allow the patient to proceed to a natural death. However, the decision should not be defined by these binary outcomes. A more compelling way to conceptualize the decision is as an expression of the will of the person involved in the dispute—a value judgment reflecting a deeper understanding of the individual.

Person-centered mediation expands on the transformative ideal of recognition to encompass not only the parties, but also the choice they face. In the transformative approach, recognition occurs primarily in the context of the other party. Person-centered mediation seeks to expand this idea of recognition by leading the parties to an enhanced awareness of the importance of the decision that gives rise to the dispute. Using EOL care as an example, the parties must achieve an understanding that they are not deciding life or death, but are building a conception of the patient and situation that will allow them to come to a decision that reflects the will of the patient. The mediation process may lead to the ancillary benefit of the parties achieving enhanced recognition of each other. However, given the limited outcomes and individual focus inherent to the person-centered mediation context, the parties must be brought to recognize the nature and importance of the decision driving their dispute.

Though the focus remains on the person at the heart of the dispute, the parties may benefit from the person-centered approach. As a result of person-centered mediation, the parties may experience moral growth from an

⁹⁰ The limits placed on options can vary according to the nature of the dispute. Child or elder care may allow for more flexibility than the often life-or-death decision involved with EOL treatment disputes.

enhanced awareness of their own condition as it relates to those around them. Through person-centered mediation, the parties are brought to recognize the significance behind value-centered judgments and experience an enhanced awareness of how this decision impacts the opposing party and others pertinent to the dispute. The experience of person-centered mediation leads not only to moral growth, but a greater understanding of the reason the parties reached a particular resolution. This greater understanding may potentially lead to heightened acceptance of the decision and allow the experience to serve as a cathartic process. Heightened understanding and acceptance are precisely the attributes of mediation that justify it as a better alternative to litigation. The judicial system views a value judgment as a binary choice. Allowing for person-centered mediation mitigates the possibility of a personal, value-centered judgment from being publicly resolved in binary fashion.

Practically speaking, the critical component of a person-centered approach to mediation is an appropriate characterization of the decision. Traditionally, a mediator describes the process as one in which he or she serves as a neutral third party to help facilitate a mutually acceptable resolution. While this still essentially holds true, the formal recognition of the process does not necessarily aid in the goals of the person-centered mediation approach. More important is the explicit recognition of the individual around whom the dispute revolves and the limited outcomes inherent to the process. Recognition of the individual and the limited outcomes serves as a building block for focusing the parties on the reality facing the individual and the gravity of the decision which must be resolved.

Throughout the course of mediation, the mediator should strive to keep the focus on an understanding of the person at the heart of the dispute. The mediator must drive the parties past their own judgments and entrenched positions and move them toward a deeper understanding of the individual centered at the dispute. A party's simple preference ("I think the patient should live") should be acknowledged by the mediator then used as an opportunity to channel the conversation back to the individual. ("I hear your opinion and understand your sentiment; but tell me how you think Mary would feel. Tell me about some of your favorite experiences with Mary.") Focusing the discourse on the non-competent individual builds a deeper understanding of the individual and ultimately, either overtly or subconsciously, brings the non-competent individual to bear on the decision to be made.

Narrative provides a key tool for achieving the objectives of person-centered mediation. The mediator's role as a neutral third party allows him or her to help shape the discourse surrounding the dispute. The mediator can use this as an opportunity to build a robust conception of the value-centered

CONSIDERATIONS IN APPLYING BIOETHICS MEDIATION

decision that drives the dispute. In the EOL care context, allowing those who know a patient to share that patient's story gives parties a more complete conception of the essence of the patient and enhances their understanding of that patient's desires for his or her medical care.

Beyond narrative, the mediator should endeavor to incorporate any method that allows the parties to experience and understand the individual. In some cases, this could involve mere physical presence with the individual. As an example, Terri Schaivo's guardian ad litem built his understanding of Mrs. Schaivo based on the time he spent with her. He stated:

I stayed with her for as long as four hours at a time, sometimes several times a day My time with Theresa was emotional and intense. I sat with her, stood by her side, held her hand, stroked her hair, cradled her head in my hands, and looked deeply and closely into her eyes. I implored, cajoled, begged, and sought to find a consistent response, any response—anything other than reflex.⁹¹

Person-centered mediation returns the focus to the individual at the heart of a dispute. By recognizing the individual and the nature of the decision to be made, this approach aids in empowering the individual and keeping the parties attuned to the gravity of their decision. What remains is how to incorporate this approach to mediation in the EOL care dispute context.

IV. BUILDING AND IMPLEMENTING BIOETHICS MEDIATION ON A PERSON-CENTERED FOUNDATION

The discussions of autonomy, Levinas's ethics, and the person-centered approach to mediation are the prerequisites to the practical goal of applying bioethics mediation to EOL care disputes. EOL care decisionmaking presents a unique clinical setting apt for mediation. EOL treatment ultimately presents a decision between life and death, with limited gradations regarding the options for how that death may occur.⁹² Bioethics mediation can help

⁹¹ Wolfson, *supra* note 1, at 18.

⁹² One commentator opposes the notion of thinking of EOL decision in terms of binary resolution. See Cohen, *supra* note 4, at 271–76. Cohen believes that mediation can identify intermediate options that remove the need for adjudication. *Id.* at 276. He gives an example of a patient who wants to die, but whose mother does not want the ventilator removed, and proposes a compromise position of leaving the ventilator in but issuing a "do not resuscitate" order. *Id.* at 258, 274. While technically an intermediate position, ultimately the decision is binary—continuing ventilation and prolonging life or removing the ventilator and facilitating the path to ending life.

accommodate the gap between traditional definitions of autonomy and the reality of the non-competent patient. In turn, the particular needs of an EOL care dispute comport well with person-centered approach to mediation. Achieving the benefits of bioethics mediation requires a careful examination of how best to incorporate these techniques into the existing EOL care dispute resolution process.

While the adjudicatory process normally is well equipped to resolve binary disputes, the intimate subject matter of EOL care, life and death, is better suited for mediation. Adjudication is predicated on many factors, including the existence of a single best answer, the consistency of process, the importance of government and public influence on decisionmaking, the application of legal norms, and party acceptance of the result.⁹³ In contrast to adjudication, mediation generally assumes that a variety of solutions are available, disputes and resolutions differ on a case by case basis, dispute resolution norms are case and party specific, and that disputes involve considerations outside of purely legal or ethical issues.⁹⁴ In light of these differences, bioethics mediation in EOL care disputes has been justified because it is less destructive to the parties involved, has heightened sensitivity to the unique features of the dispute, is more consistent with patient autonomy and self-determination, and is less publicly intrusive.⁹⁵

Person-centered mediation's focus on recognition fits well with the intimate decisionmaking implicit to EOL treatment. Disputants in EOL care scenarios are often family members or loved ones. The nature of the situation forces these people to make an emotionally charged decision potentially touching on deeply held values and beliefs. The adjudicatory process eschews considerations of these aspects of the dispute in favor of using legal principles to reach a resolution.⁹⁶ Person-centered mediation directly

⁹³ Hoffmann, *supra* note 4, at 825.

⁹⁴ *Id.*

⁹⁵ Gatter, *supra* note 4, at 1097. This is not to say that mediation in EOL care is without its critics. Gatter notes several criticisms, including concerns that mediation: "(1) will not account for the power imbalance in disputes between health care providers and patients or patients' families; (2) will not sufficiently protect the rights of patients, especially incapacitated patients; (3) will not enforce important public values; and (4) cannot resolve disputes over moral values." *Id.* See also Hoffmann, *supra* note 4, at 825. "Perhaps the greatest concern about mediation in cases involving termination of life support is that while mediation may lead the parties to a mutually satisfactory solution, it may not lead to an ethical or 'just' result." *Id.*

⁹⁶ Cohen, *supra* note 4, at 299. "The adjudicatory process attempts to frame feelings out of the dispute: adjudication is an application of legal principles to facts, a combination of syllogistic and analogic reasoning." *Id.*

CONSIDERATIONS IN APPLYING BIOETHICS MEDIATION

addresses these concerns by seeking to bring the disputants to recognize the value-laden nature of the dispute and to empathize with the opposing party. Via recognition, parties may better preserve their relationship and may achieve a higher degree of emotional satisfaction with a given resolution.

The patient recognition inherent to person-centered mediation also helps ensure that the decisionmaking process approaches giving full effect to the patient's autonomous wishes. Patient self determination is at the root of making an EOL treatment decision.⁹⁷ Person-centered mediation uses narrative and other tools to build a more complete conception of the patient. This narrative reveals more aspects of the patient and the surrounding dispute than a discussion of EOL treatment based solely on ethical, medical, or other principles. Building a rich understanding of the patient empowers decisions that are more likely to reflect the patient's desires. The narrative not only better represents the patient's autonomous wishes, but may also be cathartic to those participating.

As an ancillary benefit, a person-centered approach to bioethics mediation fits within these attributes and can be smoothly incorporated into the existing dispute resolution process. Bioethics mediation may make its way into the EOL care dispute resolution process in both a subtle and overt manner. Formal ethics consultation and bioethics mediation can be introduced early into the process, prior to an ethics committee review. More subtly, patient care personnel may receive training in mediative techniques to help aid in identifying and addressing disputes in a more informal manner.

With bioethics mediation in the fold, a model of the dispute resolution process would look as follows:

- Step 1: Resolution by compliance with advanced directive or by the uncontested decision of the appropriate family member, caregiver or legally obligated party.
- Step 2: Ethics consultation for the decisionmakers.

⁹⁷ While giving effect to patient autonomy is a generally accepted goal, (*see supra* note 67 and accompanying text), at least one commentator argues that a narrow focus on autonomy does not adequately take other important factors, such as family dynamics and justice, into consideration. Hafemeister, *supra* note 10, at 358. "An exclusive focus on patient autonomy can be insensitive to the harm it causes the family, overlook relevant family dynamics and the needs of the family and the patient, undercut the principles of beneficence and justice, and be unachievable for patients who lack decisionmaking capacity." *Id.* However, the medical conception of autonomy focuses on the patient's exercise of his or her desire for treatment. The autonomy revealed via mediation is a much more robust conception of the patient's life and wishes, more in the spirit of Levinas.

Step 3: Refer the dispute to bioethics mediation.

Step 4: Convene the ethics committee to address the dispute.

Step 5: Transition to the adjudicatory process to resolve the dispute.⁹⁸

As evidenced by the model, bioethics mediation will not likely serve as a cure-all for EOL care disputes—some may still reach a public and litigious resolution. But implementing bioethics mediation should provide a compelling alternative to aid in resolving a dispute before it reaches a public and impersonal end.

Unpacking each of these steps, training ethics consultants and providing bioethics mediation give two additional opportunities to resolve an EOL care dispute before resorting to litigation. As an initial matter, the best case scenario is that a dispute over EOL care may be resolved amongst the parties and caregiver without the need for any intervention. Bioethics mediation and associated techniques become pertinent in the steps following the failure to achieve a best case scenario result.

Ethics consultants may both aid in resolving disputes and become valuable participants in dispute resolution if the matter proceeds further. An ethics consultant can bring the parties to understand the situation medically and recognize the nature of the decision that must be made. He or she can lead the family to construct a narrative of the patient to aid in determining what the patient's autonomous wishes might be. The ethics consultant can also play a role if the dispute proceeds further. If the parties request formal bioethics mediation, the ethics consultant could participate in the process or at a minimum educate the mediator to issues of importance in the dispute.

In the event that the dispute cannot be resolved by an ethics consultation, the parties may elect to partake in bioethics mediation. At this point, the dispute is more likely to have ripened to a point where diverse parties and interests are more easily recognized. If the ethics consultant has been trained as a mediator, he or she may mediate the dispute if the patients so desire. Mediation may prove more efficient if the mediator already has a degree of familiarity with the dispute and the parties. If the parties prefer a different mediator, they may request a bioethics mediator from either within or outside the hospital. Allowing for an outside mediator may limit the opportunity for institutional bias, and help account for particular religious, personal, cultural, or other preferences relevant to the parties in making their decision.

⁹⁸ This draws from I. Glenn Cohen's proposed multi-step process for resolving EOL decisionmaking disputes. See Cohen, *supra* note 4, at 314.

CONSIDERATIONS IN APPLYING BIOETHICS MEDIATION

Where resolution cannot be achieved by mediation, the dispute will proceed to the ethics committee and, if necessary, litigation. The ethics committee should endeavor to involve the principles of person-centered mediation in rendering its opinion or decision and should be trained in person-centered mediation techniques. Specifically, the committee should understand the nature and essence of the patient. If the parties give consent, the committee could seek the input of the ethics consultant or bioethics mediator. Making an effort to deeply understand the patient may be administratively inefficient, but the unique circumstances of non-competent EOL care disputes demand extra attention. Where the ethics committee cannot conclusively resolve the dispute, the matter would proceed to litigation.

Given the EOL care environment, mediator training should be informed by person-centered mediation techniques. Training for traditional mediation focuses on aiding the parties in creating options to resolve the dispute. The traditional approach is ill suited for a limited outcome environment such as the EOL care context. Instead, mediator training should center on the attributes of the person-centered mediation approach: acknowledging the limited outcomes to the dispute, focusing the parties on the person and attendant value judgment at issue, and incorporating narrative and other techniques to construct a conception of the patient that allows the parties to reach a decision on care that gives effect to the patient's autonomy.

Mediating EOL care disputes does raise the issues of bias and impartiality. As aforementioned, the potential for a conflict of interest exists where the consultant or mediator is affiliated with the hospital.⁹⁹ Further, if a mediator strongly believes in a particular ethical position or in a particular resolution for a given case, it may adversely impact the course of the mediation.¹⁰⁰ The nature of mediation somewhat alleviates this concern—ultimately the parties reach a resolution; the mediator does not impose one. Further, allowing the parties to select the mediator also helps to alleviate bias and impartiality issues—particularly where the mediator is not affiliated with the hospital. However, conflict of interest, bias, and impartiality certainly should be addressed in training.

Bioethics mediation and mediative techniques can straightforwardly fit within the EOL dispute resolution structure. With proper training and execution, these processes may aid in resolving EOL care disputes with a more positive result for the parties involved and with greater respect for the will of the patient.

⁹⁹ See *supra* note 34 and accompanying text.

¹⁰⁰ See *supra* note 37 and accompanying text.

V. CONCLUSION

Bioethics mediation presents a compelling option to resolving EOL care disputes. For Terri Schaivo, her private dispute ended in a very public resolution. While mediation might not have countered all the external forces that came to bear on the decision regarding her care, in many cases mediation may help mitigate the potential for a public end. Both mediator-trained ethics consultants and bioethics mediators can promote an enhanced understanding of the situation, the patient, and the value-centered decision the parties must make. This enhanced understanding—seeing the face of the other—can better give effect to the patient's autonomous wishes. Additionally, it may ultimately lead to resolution of the dispute on the parties' terms, thus avoiding third party decisions by an ethics committee or court. The deeply personal considerations made during EOL care decisionmaking are best kept within the intimate family and friend relationships surrounding the patient—a goal better served by bioethics mediation.